Clinical ethics committee

J G Thornton, R J Lilford

An informal clinical ethics committee was set up to advise on ethical problems in prenatal diagnosis in Leeds. It was used twice in six months but was not called on again in the subsequent year, and we describe this experience. In North America similar committees are often used to advise on clinical moral dilemmas, and we review the published evidence from there and discuss some of the advantages and problems. Our committee's advice may have altered clinicians' actions considerably, but perhaps doctors in Britain are not yet ready to surrender this aspect of clinical autonomy.

With the exception of those concerned with assisted conception, ethics committees concerned with clinical matters are little used in Britain. In contrast they play an important part in clinical practice in the United States and Canada.[1-6] In our prenatal diagnosis practice we are occasionally faced with ethical dilemmas such as requests for feticide in the third trimester. Although the Human Fertilisation and Embryology Act allows this when there is a "substantial risk . . . [of] . . . serious handicap," we are unsure what is meant by serious in this context and uncertain how to act if parents and doctors disagree.[7] Such moral problems are increasingly common: we have recently considered requests for diagnosis of sex and paternity, for termination for cystic fibrosis or Duchenne dystrophy at residual risks below 1%, and for reducing multifetal pregnancy, often backed by the threat to terminate anyway if we refused.

We therefore set up an informal advisory group to provide independent advice in such difficult circumstances. We report our initial experience and review the literature on the use of such committees in other countries.

The ethics committee

The committee had no special authority, and its advice had the same status as that from any other professional consultation. The members consisted of a philosopher with a particular interest in applied ethics, a doctor who was a former chairman of a research ethics committee, and a senior obstetrician not involved in the case considered. They were given a written summary of the case by the referring clinician and were allowed two days to seek extra information and to consider their response. They then met for about one hour to produce a report. Two cases were considered in the first six months.

Case 1

A pregnant woman whose husband had a one in two prior risk of Huntington's chorea requested exclusion testing for the fetus. The husband was apparently unaware of his genetic risk, and his wife refused to let him be told, insisting that he might commit suicide if it was revealed. She reported that he had already had some episodes of explosive loss of temper, suggesting that he might already have early disease. She planned to obtain the necessary blood sample from him by deception and, if the fetus turned out to be at risk and she underwent abortion, to claim that she had had a spontaneous miscarriage. The pregnancy was unexpected but not unwanted, and the couple had previously undergone unsuccessful fertility treatment.

Although the wife had a history of depression, she was mentally well at that time, of above average intelligence, and seemed to have considered deeply the risks, benefits, and difficulties of her plan. Over a period of two weeks, during which she saw a clinical geneticist and genetic health visitor, she resisted all suggestions that her husband be informed and threatened to seek abortion elsewhere if her request was declined. The clinical geneticist and her obstetrician thought that she was acting in good faith but asked the committee for an opinion.

The committee unanimously recommended that the husband should not be tested without his consent. They argued that maintaining trust between doctors and patients was essential and that the obligation to avoid deception outweighed that to benefit the future child or avoid preventable distress. They were concerned that deception on this scale would threaten the marriage should it ever come to light. They all agreed that the doctors had not yet acquired a duty to inform the husband but disagreed about how much he need be told before a sample should be obtained. The philosopher recommended telling him simply that it was needed for unspecified prenatal diagnosis and possible termination, with further information being disclosed only if requested. The other two members thought that he should be told about Huntington's disease. They all agreed that, if the wife would not permit him to be told anything, then exclusion testing should be refused. If, after this, she wanted an abortion her request should be treated as would any other request for termination for personal reasons.

The wife refused to inform her husband, exclusion testing was not performed, but she did not carry out her threat to abort the pregnancy.

COMMENT

The arguments about providing information for Huntington's chorea have been well rehearsed,[8-10] and most experienced counsellors whom we consulted supported the committee's decision. They all noted that the information about the husband's initial risk should have been given to him rather than to his wife, although this observation did not help the doctors treating her, when the information had already been given. These doctors had thought that the benefit from the deception outweighed the disadvantages and that, since paternal consent is not usually demanded for prenatal diagnosis, it was inconsistent to permit the deception about abortion but not about prenatal diagnosis. However, the committee argued that the difference arose because an abortion would have

Institute of Epidemiology and Health Services Research, Leeds LS2 9LN
J G Thornton, *reader in obstetrics and gynaecology*
R J Lilford, *professor of obstetrics and gynaecology*

Correspondence to:
Dr Thornton.

BMJ 1995;311:667-9

involved the woman deceiving her husband, while exclusion testing would have included the doctors in deception.

Case 2

A married woman with one healthy son presented during her second pregnancy. A 19 week scan had been reported as normal, but a scan at 28 weeks, performed primarily to check placental location, had revealed a complex heart abnormality. The infant would be expected to appear relatively normal at birth but without treatment would inevitably die of heart failure within a few months or years. Such a death would, of course, cause the child suffering and the parents considerable distress. There was no cure, but palliative surgery was possible: multiple operations would be required, and the child would, at best, survive to its late teens or early 20s.

A week passed while further scans were performed and expert opinions were obtained, and at 29 weeks' gestation the parents requested abortion. At that stage feticide (by intracardiac potassium injection, for example) would have been necessary to prevent a live birth. The obstetrician responsible was prepared to do this but, being aware that other staff might have reservations about what would have been the first intentional termination after 28 weeks in that hospital, asked the committee for an opinion. Although the parents were given the option of seeking a second opinion if the committee advised against termination, they indicated that they would accept the committee's ruling.

The committee argued against abortion, and the child was delivered. The members argued that there was general consensus that killing of a 29 week newborn baby was wrong, and they saw no important moral distinction in the baby being still in utero. They thought that this was not a conflict between maternal rights over her own body and fetal rights to life and supported their decision by emphasising the regret that the mother might feel after abortion and the uncertainty of medical prognostication. They indicated that non-treatment of the child at the parents' request should be an option.

COMMENT

The committee's statements and reasoning can be disputed on several points. Firstly, infanticide and feticide at 29 weeks are not necessarily morally equivalent. Third party effects, such as those on other staff or people who hear about the operation, are very different. Similarly, the committee's distinction between the morality of allowing the baby to die after delivery and active killing largely depends on distinguishing between acts and omissions, discredited in many eyes. Finally, refusal of termination on the grounds that the prognosis is uncertain or that regret may occur is paternalistic, directive, and to be deplored. Nevertheless, even if non-directive counselling is recommended at earlier gestational ages termination on request is certainly illegal after viability. At early gestations parents may choose abortion for reasons that may seem trivial to others, but society will not tolerate such free choice after viability. In 1991 abortion after 24 weeks' gestation was legalised when "there is a substantial risk that the baby will be born with serious handicap," but anyone performing such abortions must indicate why they do so for some indications and not for others—that is, what is serious handicap?

In the present case there was a high probability of serious handicap, and we wonder whether the committee was not being too cautious. The obstetrician involved, though personally uncertain, inclined towards the parents' view and had an uncomfortable interview passing on the committee's verdict. Nevertheless, his emotional reaction was coloured by considerable relief that he no longer need perform the procedure.

Discussion

PURPOSES OF THE COMMITTEE

A clinical committee may be helpful in three ways. Firstly, clinicians may not know what to do and need guidance. Secondly, for reasons of prudence it may be desirable to test public opinion before acting on a decision that might provoke damaging opposition. Thirdly, although clinicians working in teams have personal views, the decision may not be entirely in their gift if the team is unable to reach a consensus. All three reasons were present to some degree in the two cases described above.

None of these reasons for involving a clinical ethics committee is likely to be uncontroversial. Firstly, use of the committee for guidance can be criticised on the grounds that other more appropriate and less bureaucratic methods exist—for example, through personal discussion with clinical colleagues or a professional medical ethicist. The use of the committee to sample, and perhaps hide behind, the views of society is also likely to be controversial. Thus, although society's views about questions of ethics have considerable practical importance, their moral importance is disputed. Lastly, use of the committee in cases when there is disagreement between professionals could be criticised on the grounds that clinicians should be able to give the care that a patient wants (or is believed to want) without interference from nursing or other staff. Nevertheless, doctors have to maintain the cooperation of colleagues in related professions to continue working. Even if they believed that parents' request for late feticide for moderate abnormalities was morally right they might soon find that, if they did this, their ability to offer abortion for more serious handicap would be curtailed. For example, some people think that giving a baby a lethal injection in utero is morally worse than inducing a medical abortion. Whether this distinction has moral importance[11] or results simply from such side effects as brutalising doctors,[12] it is important to many people and arbitration may be needed when professionals disagree.

COMPOSITION OF THE COMMITTEE

Whether a committee should include lay people, theologians, nurses, or lawyers depends on what it is being used for. If professional philosophical or legal opinion is sought then suitable experts should be present as well as experienced clinicians. If clinicians wished to test public opinion then a mixture of patients' representatives and clinicians, or even the results of an opinion survey, would be preferable. If the views of team members are wanted then they should be included with other professionals.

STATUS OF THE COMMITTEE

Although hospitals usually expect their employees to obtain authorisation for research projects from research ethics committees in accord with Department of Health guidelines, such decisions are not legally binding and a hospital could sanction clinical research without consulting a local ethics committee at all. As recommended by the American Medical Association,[13] the committee that we formed was purely consultative rather than prescriptive and thus had even less status. In practice, however, clinicians will rarely go against such a committee's advice even when they disagree with it, especially if they had sufficient doubt to ask the committee in the first place and if other stakeholders are involved.[14] Even if clinicians and patients ignore a

committee's recommendations the consultation may have usefully clarified thinking.

An ethics committee is appropriate for most problems, but if clinicians run the risk of committing a crime (for example, sterilising a mentally handicapped patient or stopping life support) then they would be better advised to seek judicial review. People who serve on ad hoc committees may be opening themselves to the risk of criminal prosecution or civil action. Certain states in the United States grant immunity from prosecution to their statutory committees.[6]

SHOULD THE TREATING CLINICIAN ATTEND?

We believe that the clinician responsible for the case under consideration should attend the ethics committee and that our structure of excluding the clinician was a mistake. Firstly, without the referring doctor the committee risks being too impartial since none of its members knows the patient concerned. Secondly, as mentioned above, it is not merely the conclusion of the committee but the argument by which it is reached that is important.

SHOULD THE PATIENT ATTEND OR BE REPRESENTED?

Problems that are presented to a clinical ethics committee are likely to have been referred because of doubt in the clinician's mind rather than doubt in the patient's; typically the issue is whether or not to accede to a patient's request. The patient's presence would be distorting if other interested parties—such as the husband in case 1—were absent. However, any committee which allowed for patients to appeal against their doctor's independent decision could invite such patients to attend. However, these committees do not have the procedural rules of a court and would need to guard carefully the interests of those not represented in any appeal procedure.

WHOSE INTEREST DO THESE COMMITTEES SERVE?

Apart from clinicians directly involved, a clinical ethics committee can serve several interests. If it is decided to carry out a distasteful procedure—such as feticide or terminating life support—the knowledge that this was a carefully considered recommendation of the committee rather than of one individual will reassure staff, relatives, and society in general. Third parties who may be affected by a patient's decision may also be particular beneficiaries. In both the cases described above the committee's final decision was based on protection of such third parties—the husband in the first case and the unborn child in the second.

One person in particular, the patient, risks being harmed by clinical ethics committees. Cases are likely to be brought forward when the doctor is uncertain whether a patient's request is permissible, and it follows that such requests may sometimes be overruled. Although this restricts patient autonomy, patients may be pleased in the long run if the committee's experience stops them harming themselves or others. It may also be a comfort to the patient to know that a declined request was considered seriously by the committee. The committee interferes with the doctor-patient relationship,[15] but any failure to accede to a patient's request also carries this danger. Committees may also reduce clinical freedom, but there are so many other constraining factors on clinical freedom (such as the attitude of other staff and managers) that there will be cases when it increases clinical freedom by bolstering the doctor's opinion.

Despite our initial enthusiasm we, like others, have major concerns about clinical ethics committees. They may systematically reach decisions to minimise their exposure to criticism.[16] If so, it would be wrong for doctors to "hide behind" such committees. A committee may come under the influence of a particular constituency or lobby that might not serve the best interests of patients or their carers. Finally the group dynamics of committees may not permit diverse views to be fully considered.[17]

OTHER SOURCES OF INDEPENDENT AND EXPERT ADVICE

It seems to us that doctors can no longer take important ethical decisions on their own, especially when they disagree with the request of a patient or a patient's surrogate. On the other hand a committee seems remote and impersonal and may be subject to the bias mentioned above. The use of ethical consultants skilled in communication, negotiations, relevant law, and the principles of medical ethics and who have medical knowledge may be preferable; initial experience in the United States suggests that this alternative has promise.[14 18-20] Finally, some authors have advocated a compromise similar to the structure we used, of small teams giving an ethical consultation.[21]

We would welcome comments from others regarding clinical ethics committees. Our committee almost certainly changed practice for both cases, with what some would perceive as serious net negative consequences. Many doctors in Europe will argue that these committees should stay on the other side of the Atlantic, and our committee has not been used since the cases described here over a year ago. Were we ahead of our time?

We thank Ms Jennifer Jackson, director of the Centre for Professional and Business Ethics, University of Leeds, for discussion.

1 Fost N, Cranford RE. Hospital ethics committees: administrative aspects. *JAMA* 1985;253:2687-92.
2 Rosner F. Hospital medical ethics committees: a review of their development. *JAMA* 1985;253:2693-7.
3 Perkins HS, Saathoff BS. Impact of medical ethics consultations on physicians: an exploratory study. *Am J Med* 1988;85:761-5.
4 Andereck WS. Development of a hospital ethics committee: lessons from five years of case consultations. *Camb Q Health Ethics* 1992;1:41-50.
5 Moss AH, Stocking CB, Sachs GA, Siegler M. Variation in the attitudes of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. *J Am Soc Nephrol* 1993;4:229-34.
6 Fleetwood J, Unger SS. Institutional ethics committees and the shield of immunity. *Ann Intern Med* 1994;120:320-5.
7 Lilford RJ, Thornton JG. Ethics and late termination of pregnancy. *Lancet* 1993;342:499
8 World Federation of Neurology and Research Group on Huntington's Chorea. Ethical issues policy statement on Huntington's disease molecular genetics predictive test. *J Neurol Sci* 1990;94:327-32.
9 Harper PS, Morris MJ, Tyler A. Genetic testing for Huntington's disease. *BMJ* 1990;300:1089-90.
10 Tyler A, Morris M. National symposium on problems of pre-symptomatic testing of Huntington's Disease, Cardiff. *J Med Ethics* 1990;16:41-2.
11 Lilford RJ, Johnson N. Surgical abortion at 20 weeks. Is morality determined solely by outcome? *J Med Ethics* 1989;15:82-5.
12 Thornton JG. Morality of surgical abortion at 20 weeks. *J Med Ethics* 1990;16:53-4.
13 Judicial Council of the American Medical Association. Guidelines for ethics committees in health care institutions. *JAMA* 1985;253:2698-9.
14 Perkins HS. Clinical ethics consultations: reasons for optimism, but problems exist. *J Clin Ethics* 1992;3:133-5.
15 Sonnenblick M, Friedlander Y, Steinberg A. Dissociation between the wishes of terminally ill parents and decisions by their offspring. *J Am Geriatr Soc* 1993;41;599-604.
16 Carter BS. Neonatologists and bioethics after Baby Doe. *J Perinatol* 1993;13:144-50.
17 Lo B. Behind closed doors. Promises and pitfalls of ethics committees. *N Engl J Med* 1987;317:46-50.
18 La Puma J, Toulmin SE. Ethics consultants and ethics committees. *Arch Intern Med* 1989;149:1109-12.
19 Anzia D, La Puma J. Cultivating ethics consultation. *J Clin Ethics* 1992;3: 131-7.
20 Simpson KH. The development of a clinical ethics consultative service in a community hospital. *J Clin Ethics* 1992;3:124-8.
21 Swenson MD, Miller RB. Ethics case review in health care institutions. Committees, consultants, or teams? *Arch Intern Med* 1992;152:694-7.

(Accepted 2 June 1995)